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Literature Review of Information-Seeking Behavior and Decision Making of Women with Breast Cancer

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Aim: The aim of this study was literature review to describe the theoretical and empirical relevance of information-seeking behavior and decision-making of women with breast cancer.

Background: Breast cancer patients have complained that their information needs were not being adequately met.

Methods: Searches were conducted on the PubMed and ICHUSHI databases from 1990 to 2010 using the key word phrase “information seeking behavior and breast cancer and decision making.” PubMed showed 12 matches, but ICHUSHI showed none, so the key word search the literature was broadened to “information seeking AND breast cancer” and “decision-making AND breast cancer.”

Results: The studies were classified thematically according to the information-seeking behavior concept, information needs, and decision-making preference and experience. First, the author discusses the concept and importance of information-seeking behavior. Second, the author addresses breast cancer patients information needs and sources. Third, the relevance and assessment of preference and experience are discussed.

Conclusion: Information-seeking is thought to be part of the problem-solving process that is aimed at achieving the goals of receiving the best medical treatment, recovering from illness, and improving a patient s health and quality of life. Information-seeking is an important part of decision making with regard to treatment selection and coping with cancer. The information sought by breast cancer patients varies depending on the individual. The information-seeking experience was evaluated based on patients information needs, hopes, decision-making preferences, and subjective satisfaction rating.

Key words : information-seeking behavior, information needs, decision-making preference, information seeking experience

Introduction

Because of the spread of the Internet, most people can now obtain information, but they do not know whether the available information is reliable. Information is defined as “an informing or being informed, a telling or being told of something; news; intelligence; word”, “knowledge acquired in any manner; fact; data; learning”, “a person or agency answering questions as a service to others”[1].

Ishigami described that the meaning of information provided by researchers should emphasize four common factors: evaluation, acceptance, difference between information and data, and strong relationship to knowledge[2]. Brookes regarded knowledge as a structure of concepts linked by their relationships and information as a small part of such a structure. The fundamental equation $K[S]+\triangle I = K[S+\triangle S]$ states in its very general way that the knowledge structure ($K[S]$) is changed to the new modified structure $K[S+\triangle S]$ by the changes in information, $\triangle I$[3]. Information may, of course, depend on sensory observation, but the sense data so received must be subjectively interpreted

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based on a knowledge structure to become information[3]. Thus, information is considered to induce changes in our knowledge after we have learned and interpreted the information.

Breast cancer is the most common cancer of women in their 40s – 60s. A rapid increase in incidence rate was seen among the middle and old age groups, especially among women 45-54 years old [4]. There are a number of effective treatments for breast cancer, so patients are often confused by the treatment choices. Over the past 10 years, breast cancer treatment has improved survival and health-related quality of life (HRQOL). When making decisions about the treatment for breast cancer, it becomes important to obtain appropriate information. Most doctors provide medical information in accordance with the guidelines for breast cancer treatment, but patients may wonder whether the choice of treatment should be made by the patients themselves or by the physicians.

The aim of this review was to collect and discuss literature about breast cancer as it relates to how and why to obtain information, what particular types of information patients need, where they can find the information, how the information is used, and what patients experiences are with decision-making after accessing information.

Methods

Sample for data collection

Searches were conducted on as above from 1990 to 2010 using the key word phrase "information seeking behavior and breast cancer and decision making." PubMed showed 12 matches in the English literature. Then a perusal of the reference lists of each literature was conducted to retrieve potentially relevant studies not identified. ICHUSHI showed none, so the key word search in the Japanese literature was broadened to "information retrieval AND breast cancer" and "decision-making AND breast cancer." There were 73 matches for the first phrase and 6 for the latter phrase. The nursing studies found with the key words "decision-making AND breast cancer" were mainly narrative studies. The 73 matches for the first phrase were mainly discussions of genetic tests and treatments in the pathology field. These studies were excluded from the present study, and the literature reviewed for this analysis included books, review articles, empirical studies, meeting abstract, and brief commentaries. The chosen literature was written in English or Japanese, and included "information seeking" or "decision making" in the title or key words.

Data analysis

The author read each piece of retrieved literature to understand the concept or the key characteristics of information-seeking behavior. The studies were classified thematically according to the information-seeking behavior concept, information needs and sources, and decision-making preference and experience. Here the author discusses how and why patients obtain information, what particular type of information was needed, where patients retrieved the information, how the information was used, and types of decision-making and experiences.

Findings

The concept of information-seeking behavior

Though "information retrieval" is defined in the dictionary, there is no entry for "information seeking." "Information retrieval" is the term used to describe looking for specific information[5]. There is no explicit definition of information seeking behavior. Miwa said that information retrieval occurs at the micro level, while information seeking occurs at the macro level, and the highest macro level is problem solving. Between a human and the specific information system for searching information, seeking information includes looking to acquire knowledge gained from exploring the information and interacting with it sequentially[6]. The term "information seeking" developed from the field of library informatics and cognitive science. Lenz[7] was the first to discuss information seeking in the field of nursing. Information seeking is an important antecedent to health-related decisions and behavior.

In Lenz s study, the concept of information seeking is analyzed within the framework of a six-step process model: (1) a stimulus, (2) goal setting, (3) a decision regarding whether to seek information actively, (4) search behavior, (5) information acquisition and codification, and (6) a decision regarding the adequacy of the information acquired[7]. Inter-related dimensions of the information search process are identified, and the impact on cognitive and behavioral outcomes is postulated[7].

The meaning of the term “information seeking” may appear to be obvious; others use the term “health-related information seeking”[8] . Fukuda et al. identified three categories of health information seeking behavior in working women: 1) being aware of and caring for one's physical and psychological well-being, 2) collecting information, and 3) utilizing information[9]. Various definitions of information seeking in the literature are shown in Table 1.

Table 1 : Definitions of Information Seeking

Author	definitions related to imformation-seeking
Elizabeth R. Lenz (1984)[7]	The information-seeking patterns of clients have received little attention in nursing theory and research, but they are important antecedents of health-related decisions and behavior. The concept of imformation seeking is analyzed within the framework of a six-step process model. Interrelated dimensions of the information search process are identified,and the impact on cognitive and behavioral outcomes is postulated.
Virginia M. Conley (1998)[10]	The phrase″information-seeking behaviors″is proposed as an alternative diagnosis. It meets the criteria for a nursing diagnosis. The concept of″Information-seeking behaviors″provides a diagnosis that promotes individualized nursing interventions based on patient indicators of significance and need.
Dale E Brashers et al.(2002)[11]	Information seeking and avoiding may be a balancing act for individuals who need to achive multiple goals. An important contextual feature is the channels of communication available for information seeking and providing.Individuals seeking information for health care decision-making need help interpreting what they find on websites and resolving inconsistencies between discrepant ″facts″about illness and treatments.The final goal of a normative model is to identify ways of addressing challenges and dilemmas of communication.
Sylvie D. Lambert et.al.(2007)[8]	Health-related information-seeking behavior is studied within the context of (a) coping with a health-threatening situation, (b)participation and involvement in medical decision-making, and (c) behavior change and preventive behavior.
Sylvie D. Lambert, Carmen G.Loiselle, Mary Ellen Macdonald(2009)[12] [13]	Five health information-seeking behaviors patterns were identified: (1) intense information seeking-a keen interest in detailed cancer information; (2) complementary information seeking-the process of getting″good enough″cancer information; (3) fortuitous information seekng-the search for cancer information mainly from others diagnosed with cancer; (4) minimal information seeking-a limited interest for cancer information; and (5) guarded information seeking the avoidance of some cancer information. Patients varied in their reasons for seeking cancer infomation, as well as in the type, amount, and sources of cancer information sougut and the information management strategies used.

Informing a patient that she has cancer creates a threatening and stressful situation. Brashers et al. inferred that information management includes avoidance and information-seeking behavior[11] to cope with the stressful situation. Information avoidance is negative, but it is one strategy for coping with a problem. The concept of information management is shown in Fig. 1. Information provision is, for example, educating cancer patients about illness and treatment from a doctor and nurse.

Many researchers have studied how to cope with cancer. Lambert noted that health-related information-seeking behavior occurs within the context of (a) coping with a health-threatening situation, (b) participation and involvement in medical decision making, and (c) making behavior changes and participating in preventive behavior[8]. Thus, definitions of information seeking are tied to the purpose of seeking health-related information.

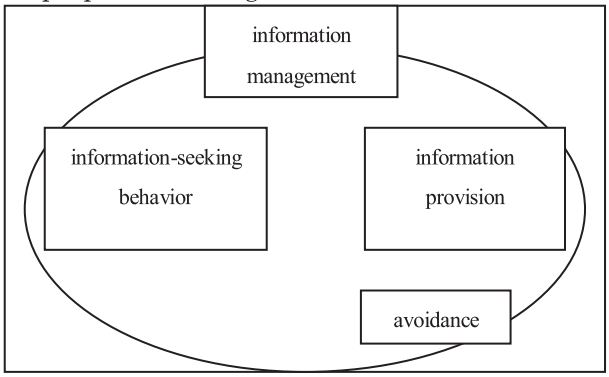

Fig.1. The information-seeking concept

Information needs and source

Many researchers have studied the information needs of women with breast cancer. Breast cancer patients need information about their illness, treatment, treatment side-effects, prognosis, the recovery process, common symptoms, and treatment costs. They also need to know about recovery after surgery. They need to be informed about the emotional supports available to them after discharge (Nara & Kudo, 2005)[14].There is scant reference to the need for information on other issues, such as available financial and community resources, or coping strategies (Vander Molen,1999)[15]. According to one study, breast cancer patients felt there was a lack of support in four categories: onset and severity of household tasks and work after discharge, information on the contents of a healthful dietary intake, notes on life during and after treatment, and information about treatment side effects and how to deal with them (Ueda, 2008)[16]. All patients wanted basic information on diagnosis and treatment, while not all of them wanted further information during all stages of their illness (Leydon et al, 2000)[17]. Women younger than 50 years rated information about physical and sexual attractiveness as more important than did older women, while women older than 70 years rated information about self-care as more important than did younger women, and women who had a positive family history of breast cancer rated information about family risk as more important than did other women (Denger et al, 1997)[18]. Information needs regarding illness, treatment, and side effect were common to all women with breast cancer, though needs differed from one individual to the next and varied from pre-operation to post-operation.

Doctors and nurses were expected to respond to patients needs regarding "information service, consultation," “a social activity along with learning” (that is, self-help groups), and "mental support" (Nishida et al, 2008)[19]. Self-help groups were expected to be an "information service" and a "social activity along with learning" (Nishida et al, 2008)[19]. Thus, Self-help groups have played important role for information seeking patients with breast cancer. However, approximately, 70% of breast cancer patients reported obtaining information from a source other than the treatment staff(Walsh MC et al, 2010) [20]. Significant predictors of using additional information sources included younger age, higher income and education, complementary and alternative medicine use, and reporting shared decision making. Women with breast cancer who have a college degree were more likely to use the Internet (Walsh MC et al, 2010) [20]. The Internet is used by patients with breast cancer, and such use has increased in recent years. Among eight types of information media, brochures, television, and the Internet were ranked as the most important sources of information. Among breast cancer patients, 41% used the Internet themselves or via friends or family, mostly to research classic and alternative treatment options. Unavailability of a computer and the necessity of computer skills were the most frequently mentioned obstacles to Internet searching (Adler et al 2009) [21]. In one study, information media were used considerably by the study participants and were important contributors to knowledge and facilitators for decision making (Balmer, 2005) [22]. In another study, patients used the Internet to get information on the disease and treatment options, to get information about other survivors' experiences, and to reduce anxiety related to having cancer and undergoing treatment (Matsumoto et al, 2005)[23]. It is clear that the Internet offers many positive possibilities, including a new source of consumer advocates and participants in patient involvement in healthcare policies, research, and management. (Ziebland, 2004)[24].

Preference of decision making

A 1993 nursing study put decision makers into one of three empirically derived groups, Deferrers, Delayers, and Deliberators (Pierce, 1993) [28]. A 1997 study revealed decisional preferences in women with breast cancer were categorized by the patient

taking an active role, a collaborative role, or a passive role (Denger et al, 1997) [18]. These preference roles are represented in the following typical quotes.

Active role:

A; "I prefer to make the decision about which treatment I will receive."

B: "I prefer to make the final decision about my treatment after seriously considering my doctor s opinion."

Collaborative role

C: "I prefer that my doctor and I share responsibility for deciding which treatment is best for me."

Passive role

D: "I prefer that my doctor make the final decision about which treatment will be used, but seriously consider my opinion."

E: "I prefer to leave all decisions regarding treatment to my doctor." (Denger et al, 1997) [18].

Studies that used the concept of preferences in decision making related to breast cancer are listed in Table 2. In a recent study, Almyroudi et al showed that 71.1% of Greek women with breast cancer wanted to play a passive role in treatment decisions, whereas only 4.6% chose an active role (Almyroudi et al, 2010) [30]. However, a study of Canadian women with breast cancer showed that 22% of breast cancer patients preferred to take an active role (Denger et al, 1997)[18]. Thus, patient s decision-making preferences were different depending on patient nationality. Other factors associated with patients decision-making preferences were the patient age, education level, employment status, and amount of desired information detail (Almyroudi et al, 2010) [30]. In addition, 37.4% of women with breast cancer did not want to get detailed information, with half of them wishing to avoid awareness of bad news. A preference for a passive role was associated with wanting less informational detail (Almyroudi et al, 2010) [30].

Experience

Searching for information on cancer anywhere, many people without cancer have reported negative experiences, including the search process requiring a lot of effort, expressing frustration, and concerns about the quality of the information found (Arora et al, 2008)[33]. Everyone has good, bad, mixed experiences when they sought cancer-related information. As same as people without cancer, patients with cancer were provided information or sought it, which caused them to "have experiences". In a qualitative study , Pierce described that five empirical indicators of decision-making behavior occur during cancer-related information-seeking experiences, as follows: (a) perceived salience of alternatives, (b) decision conflict, (c) further information seeking, (d) risk awareness, and (e) deliberation (Pierce, 1993) [28]. In an other qualitative study, McCaughan and McKenna identified that information-seeking seemed to be a journey of 'never-ending making sense' with ongoing discovery and new information needs, with the information seeker going through the following three stages: 'being traumatized,' 'taking it on,' and „‡aking control' (McCaughan & McKenna, 2007)[34]. Many studies revealed that information seekers reported problems such as confusion/stress associated with receiving too much information, and misunderstanding and conflicts (Matsumoto et al, 2005)[23], and that they struggled with the efforts of understanding the disease and the treatment (McCaughan & McKenna, 2007)[34]. In one study, more symptoms of depression were associated with worse information-seeking experiences (Beckjord et al, 2008)[35]. Another study reported that patients avoid information to escape feelings of negativity and depression (Rees & Bath, 2001) [36]. The information- seeking behaviors of women with breast cancer are highly individualistic, with some women wanting information, others avoiding information, and many women fluctuating between information seeking and information avoidance (Rees & Bath, 2001) [36]. Arora developed a six-item Information Seeking Experience (ISEE) scale that included the following four items: "You wanted more information but did not know where to find it," "It

Table 2: Preferences related to decision-making by breast cancer patients

Author	Subjects	Methods	Results
before diagnosis			
Budden LM et al.[25]	366prediagnostic of Australian women	Participants were given a questionnaire about their treatment choices for early breast cancer while wating for their mammography screening. The data was collected using the Pre-Decision Portfolio Questionnaire (PDPQ), which includes the Michigan Assessment of Decision Styles(MADS).	Participants showed a variety of preferred decision styles, according to age,education and employment status. They indicated that it was important to "get the treatment over as soon as possible"36%, "participate in selecting treatment"55%, and "read a lot of information"53%.
Wendy Levinson et al [26]	2765 sample of English-speaking adults	In a cross-sectional study, participants expressed preferences ranging from patient-directed to physician-directed styles on each of three aspects of decision making (seeking information, discussing options, making the final decision). Logistic regression analysis was used to assess the relationships between demographic variables and health status and preferences.	In total, 96% of respondents preferred to be offerd choices and to be asked their opinions. However, 52% preferred to leave final decisions to their physicians, and 44% preferred to rely on phycisians for medical knowledge rather than seeking out information themselves. Women who were more educated and healthier were more likely to prefer an active role in decision making. African-American and Hispanic participants were more likely to prefer to passive role. An active role increased with age up to 45 years, but then declined.
after diagnosis			
Suzanne M.Miller [27]	article reviews	The Monitor-Blunter Style Scale hes been used extensivly to assess and categorize patients with regard to coping styles to predict their differential responses to various cancer-related screening and management regimens.	Patients defined by a monitoring coping style generally are more concerned and distressed about their cancer risk, experience greater treatment side effects. They are more knowledgeable about their medical situation, and are less satisfied with and more demanding about the psychosocial aspects of their care. They prefer a more passive role in clinical decision making. And they are more adherent to medical recommendations, and manifest greater psychologic morbidity in response to cancer-related threats.
Penny F. Pierce[28]	48women with early stage breast cancer	A qualitative analysis derived from grounded theory was used to study the clinical problem of decision making.. Patients were asked an open-ended semi-structured interview while they were making decisions.	These interviews identified five empirical indicators of decision-making behavior: (a) perceived salience of alternatives, (b) decision conflict, (c) information seeking, (d) risk awareness, and (e) deliberation. The configurations of these indicators discriminated the decision maker into one of three empirically derived following groups; Deferrer, Delayer, and Deliberator.
Lesley F.Denger et al[18]	1012women with a confirmed diagnosis of breast cancer	A cross-sectional survey, with the following measures was used : (1)preferences about various levels of patisipation in treatment decision making; (2)the extent to which subjects believed they had achieved their preffered levels of involvement in decision making; and (3) priority needs for information and how these needs differed by selected sociodemographic, desease, and treatment variables	A total of 22% of patients wanted to select their own cancer treatment, and 44% wanted to select their treatment collaboratiely with their physicians. In all 42% of women believed that they had achieved their preffered role. Patients younger than 50 years rated information about phycisical and sexual attractiveness as more important than older patients. Women older than 70 years rated inforamtion about self-care as more imprtant than did younger women. They who had a positive family history of breast cancer rated information about family risk as more imporatant than did other women.
Barbara A. Vogel et al[29]	135German breast cancer patients	Participants were asked to complete a self-explanatory questionnaire at baseline and 3 and 6 months later.	The quality of received information from the physician was rated significantly better at baseline than 6 months later. Half of all patients changed their decision- making preference at points. On average, 38% of the patients preferred passive,27% wished to share the decision, and 35% preffered active.
Augoustina Almyroudi et al.[30]	329breast canser patients.	In this cross-sectional study, the contorol preferences scale and Cassileth's information styles questionnaire were used.	In all, 71% of patients prefered to play a passive role in treatment decision making. 45% of patients wanted to delegate complete responsibility of the decision making to their doctor. 24% of patients prefered a shared role, and 4.6% of patients select an active role. At the same time, 63% women expressed a general desire to obtain as much information as possible about their illness. 37% of patients did not want detailed information; instead, they wished to avoid awareness of bad news. Women who desired fewer informational details and preferred a passive role less frequently requested mammography.
Katharine Kastbade Hughes[31]	71women with stage Ⅰ or Ⅱ breast cancer	The amount and the nature of information were recorded using an observer checklist. Recall of information and final treatment selection were ascertained during telephone interviews conducted six to eight weeks after surgery.	Subjects' selection of treatment was not related to the amount of information they received during the clinic visit. The mannner of presentation did not influence the treatment selection. However, the treatment choice was related to the amount of information they received prior to their clinic visit.
Nehama Lewis, Stacy W Gray, Derek R.Freres, Robert C.Hornik[32]	1594with breast, prostate, and colon cancer diagnosed in 2005.	Participants returned mail surveys in Fall 2006. The survey included 61 questions.	Bringing information into physicians and being referred to other sources reflects patients' engagement with health imformation, and prefrence for decision making. Seeking and scanning for preferens reflects patients' engagement with health information, preference for control in decision making, and seeking and scanning for cancer-related information.

Table 3: The information-seeking experiences of patients with breast cancer

Author	Subjects	Methods	Results
before diagnosis			
Ellen Burke Beckjord, et al.[35]	5589American households.	2627of them were asked symptoms of depression and cancer worry stimulated a negative effect; attention to health inforamtion and cancer information-seeking experiences stimulated information processing.	Higher cancer worry related to paying more attention to health information and having worse cancer information-seeking experiences. Higher depression were associated with worse information-seeking experiences, but not with the amount of attention paid to information seeking. For cancer prevention and control,inforamtion plays a vital role in promoting publis health.
Neeraj K. Arora, et.al[33]	6369nationally representive sample of individuals in the USA	In cross-sectional data from the National Cancer Institute's 2003 Health Information National Trends Survey, participants were assessed regarding whether they had ever sought cancer-related information and ratings of their information-seeking experiences and beliefs regarding causes of cancer and its prevention were examined.	In all, 55% of Americans had searched for cancer information. Many of participants reported the folloeing negative experiences, including the search process requiring a lot of effort (48%), causing expressing frustration (41%), and having concerns about the quality of information found (58%). participants of repoting more negative experiences were more likely to show that almost everything caused cancer, that not much can be done to prevent cancer, and that it is difficult to know which cancer prevention recommendations to follow.
after diagnosis			
Penny F. Pierce[28]	48women with early stage breast cancer	A qualitative analysis derived from grounded theory was used to study the clinical problem of decision making.. Subjects participated in an open-ended semi-structured interview while they were making decisions.	These interviews identified five empirical indicators of decision-making behavior: (a) perceived salience of alternatives, (b) decision conflict, (c) information seeking, (d) risk awareness, and (e) deliberation.
Charlotte E. Rees, Peter A.Bath[36]	156women with breast cancer took part in a mailed survey. 30women with breast cancer partisipated in thre focus group discussions.	A mailed survey was conducted to examine the information-seeking behaviors of participants. Focus group methodology was employed to collect in-depth data on the views of women with breast cancer concerning their information-seeking behaviors.	The information-seeking behaviors of participants are highly individualistic, some women wanting information, others avoiding information, and many women fluctuating between information seeking and information avoiding. They sought information to cope with breast cancer, regain a sense of control, increased their feelings of confidence, and helped facilitate the decision-making process.On the contary, they avoided information to escape negative feelings and depression.
Judith Belle Brown et al[37]	152women regading decision-making about their health are reflected in the three studies.	Three qualitative studies were gathered in seven sites across Ontario, Canada. Each of the studies used the qualitative reserch strategy of focus groups. A semi-structured interview guide was used in each of the studies to explore the opinions, feelings, ideas, and experiences relevant to the specific study question.	The women initiated the dcision-making process by engaging in information-seeking behavior. They desired to share the decision-making and described the outcomes when this was lacking. They recognized their need to assume responsibility for the consequences, known or unknown, in light of the decision(s) they finally made.
Matsumoto A. et al.[23]	148responds of 817breast cancer survivors with the members of a mailimg list	Participants were asked about their initial expectation of and actual experiences of the use of the Internet as an information and support resource.	Participants used the Internet to seek information on the disease and treatment options, other suvivors'experiences, and to reduce anxiety related to having cancer and treatments. Some of them noted confusion/stress associated with receiving too much information,and misunderstanding and conflicts in using e-mails and mailimg lists due to the lack of non-verbal communication were problems.
Eilis McCaughan, Hugh McKenna[34]	27newly diagnosed patients	In this qualitative study with a grounded theory approach, participants were interviewed in their own homes.	Participants' information-seeking behavior seemed to be a journey of 'never-ending making sense' with ongoing discovery and new information needs as they struggled with the efforts of the disease and treatment. The author identified three stages of information seeking as follows: 'being traumatized', 'taking it on', 'taking control'.
Sylvie D. Lambert, Carmen G.Loiselle, Mary Ellen Macdonald[12), 13]	31 men and women diagnosed with breast, prostate, or colorectal cancer	In a qualitative study; using the grounded theory approach by Strauss and Corbin, paticipants were interviewed in thirty individual interviews and 8 focus groups.	Five health information-seeking behaviors(HISB) patterns were identified: (1) intense information seeking-a keen interest in detailed cancer information; (2) complementary information seeking-the process of getting"good enough"cancer information; (3) fortuitous information seekng-the search for cancer information mainly from others diagnosed with cancer; (4) minimal information seeking- a limited interest for cancer information; and (5) guarded information seeking-the avoidance of some cancer information. (1)-(3)HISB were active information-seeking, (4) and (5) were disinterest and avoidance.

took a lot of effort to get the information you needed," "You did not have the time to get all the information you needed," and "You felt frustrated during your search for the information." These four items were used to assess the process of information seeking. Two additional items assessed the actual information found: "You were concerned about the quality of the information" and "The information you found was too hard to understand" (Arora, et al, 2008)[33]. Thus, many cancer patients experience anxiety, conflict, and confusion. However, some women sought information to cope with breast cancer, regain a sense of control, increase their feelings of confidence, and help facilitate the decision-making process (Rees & Bath, 2001) [36]. This range of experiences is depicted in Table 3.

Discussion

This literature review study describes the theoretical and empirical relevance of information-seeking behavior and decision- making of women with breast cancer. There was no clear difference in information seeking and information retrieval among the studies conducted in Japan. A definition of information-seeking for cancer patients is inferred based on the purpose of seeking health-related information, and the information-seeking behavior of patients with breast cancer is thought to be part of a problem-solving process to achieve the goal of receiving the best medical treatment, recovering from illness, and improving health and quality of life. Thus, the information-seeking behavior and decision- making are relevant for quality of life of patient with breast cancer. However, it can be inferred that the cultural context influences the information-seeking behavior and the decision making. For example, in Europe and America the decision making is driven by individualism, while in Japan that is different. An investigation to clarify the importance of cultural context in information-seeking behavior and the treatment decision- making process is needed.

The typical cancer patient seeks information that will be curative. Of course, the medical treatment staff provides breast cancer patients with information about their disease and treatment. However, many patients request more information. The information sought is various, and is different depending on the individual. The information-seeking experiences have been caused by the patient s information needs, the patient s hopes and decision-making preferences, and by the subjective satisfaction rating of breast cancer patients. Information needs arise to cope with breast cancer. Recently, for example, the number of patients with prostate or breast cancer has increased in Japan, and patients must select the best treatment among many treatment methods. As revealed in one study, information-seeking individuals naturally focused their efforts toward obtaining "all" available information about treatment options, and they wanted the "best" or most up-to-date" information (Lambert et al, 2009)[12]. As participants in treatment decision making, they had to seek the most complete information about their disease and treatment, but because it is difficult to make a decision about treatment, they struggled with an important problem that would affect their lives. For patients with breast cancer, it is important to make the best possible decision, because if the types of cancer cells are triple negative, the risks of cancer recurrence rise. Recent reports are mainly about genetic testing and treatments in the pathology field. Not only specific cancer information, but genetic information will become important for the breast cancer patient in the future.

Many cancer patients experience anxiety, conflict, and confusion (Matsumoto et al, 2005)[23] (McCaughan & McKenna, 2007)[34] but regain a sense of control and increase their feelings of confidence and help facilitate the decision-making process following information seeking (Rees & Bath, 2001) [36]. In one study, Adachi noted that the social support provided when treatment was selected could be consolidated in an emotional or informational support group (Adachi et al, 2010) [38]. In another study of advanced breast cancer patients perception of decision making for palliative chemotherapy,

Grunfeld et al, described that women offered second-line chemotherapy were more likely to undergo chemotherapy because of the hope it offers and were more likely to take an active role in that decision compared with women who were offered first-line chemotherapy (Grunfeld et al, 2006)[39]. The subjective satisfaction rating of breast cancer patients is influenced by feelings about the decision-making process. Additionally, the subjective satisfaction may be influenced by mutual trust between the doctor and the patients, and social support.

Lambert. et al described the information-seeking behaviors patterns as follows: (1) antecedents: reasons for information seeking; (2) essential characteristics: type, amount, and sources of information sought and information management strategies; and (3) outcomes (Lambert. et al, 2009)[12]. Thus, it is important to research the relevance of information-seeking behavior, what kind of cancer-related information, information resource, demographic factors, the preference of decision-making and the satisfaction rating concerning information- seeking.

During each part of the information- seeking process, patients will experience a wide range of feelings, and learn by experience. However, in the future, it is necessary to reveal the relationship between information seeking and decision making according to the disease progression, and to promote an effective information-seeking process.

References

1) Webster's New World College Dictionary, 4th ed., 733, Macmillan, 2001.
2) Mari Ishigami: Usage and meaning of 'information' in Japanese, Library and Information Science, 32, 17-41, 1994.
3) Bertram C. Brookes: The foundations of information science.Part 1. Philosophical aspects, Journal of Information Science, 2, 125-133, 1980.
4) http:// ganjoho. ncc. go. jp/data/public /statistics/2010
5) Psychological Dictionary, 382 Heivonsha, 2001.
6) Makiko Miwa: Skills of information retrieval -how to solve the unknown problem (in Japanese), Tokyo, Chuokoron- shinsa, 47-53, 2005.
7) Elizabeth R. Lenz: Information seeking: a component of client decisions and health behavior, Advances in Nursing Science, 6(3), 59-72, 1984.
8) Sylvie D. Lambert, Carmen G. Loiselle : Health information-seeking behavior, Qualitative Health Research, 17(8), 1006-1019, 2007.
9) Noriko Fukuda, Naoko Arimori, Kimiyo Takeda, Ayaka Maruyama, Hiroko Katsura : Health information seeking behavior of working women, Journal of the St. Luke's Society of Nursing, 12(1), 18-24, 2008.
10) Virginia M. Conley: Beyond knowledge deficit to a proposal for information -seeking behaviors, Nursing Diagnosis, 9(4), 129-135, 1998.
11) Dale E Brashers, Daena J. Goldsmith, Elaine Hsieh : Information seeking and avoiding in health contexts, Human Communication Research, 28(2), 258-271, 2002.
12) Sylvie D. Lambert, Carmen G. Loiselle, Mary Ellen Macdonald: An in-depth exploration of information-seeking behavior among individuals with cancer.
Part 1: Understanding differential patterns of active information seeking, Cancer Nursing, 32(1), 11-23, 2009.
13) Sylvie D. Lambert, Carmen G. Loiselle, Mary Ellen Macdonald: An in-depth exploration of information-seeking behavior among individuals with cancer.
Part 2: Understanding patterns of information disinterest and avoidance, Cancer Nursing, 32(1), 26-36, 2009.
14) Akiko Nara, Ryoko Kudo: Information needs of breast cancer patients in pre- & post-operation periods, Journal of the Japan Society of Nursing, 14(2), 51-60, 2005.
15) B. Vander Molen: Relating information needs to the cancer experience: 1. Information as a key coping strategy, European Journal of Cancer Care, 8, 238-244, 1999.

16) Chiyoko Ueda: Patient satisfaction with nursing care of breast cancer surgery focusing on information support (in Japanese), Journal of Japanese Society of Cancer Nursing, 22, 206, 2008.
17) Geraldine M. Leydon, Mary Boulton, Clare Moynihan, Alison Jones, Jean Mossman, Markella Boudioni, Klim McPherson : Cancer patients' information needs and information seeking behaviour: in depth interview study, British Medical Journal, 320(1), 909-913, 2000.
18) Lesley F. Denger, Linda J. Kristjanson, David Bowman, Jeffrey A. Sloan, K. C. Carriere, Barbara Bilodeau, Peter Watson, Bryan Mueller: Information needs and decisional preferences in women with breast cancer, JAMA, 277(18), 1485-1492, 1997.
19) Naoko Nishida, Yatoi Yagi, Rika Shimada, Emika Kuragaichi : Expected support among breast cancer outpatients from self-help groups and medical providers (in Japanese), Kyoto Prefectural University of Medicine, 17, 23-30, 2008.
20) Matthew C. Walsh, Amy Trentham-Dietz, Tracy A. Schroepfer, Douglas J. Reding, Bruce Campbell, Mary L. Foote, Stephanine Kaufman, Morgan Barrett, Patrick L. Remington, James F. Cleary ; Cancer information sources used by patients to inform and influence treatment decisions, Journal of Health Communication, 15, 445-463, 2010.
21) Johannes Adler, Yvonne Paelecke-Habermann, Patrick Jahn, Margarete Landenberger, Bernd Leplow, Dirk Vordermark : Patient information in radiation oncology: a cross-sectional pilot study using the EORTC QLQ-INFO26 module, Radiation Oncology, 40(4), 2009 http://www.ro-journal.com/content/4/1/40.
22) Claire Balmer: The information requirements of people with cancer: where to go after the "patient information leaflet," Cancer Nursing, 28(1), 36-44, 2005.
23) Matsumoto A, Aragaki M, Ying Fang Zheng, Inokuchi T, Sakai K, Shiota S, Takano M, Takahashi M : How Japanese breast cancer survivors perceive the Internet as a health information resource: an Internet survey with a mailing list participant, Iryoujyouhou- gaku, 25(3), 151-159, 2005.
24) Sue Ziebland: The importance of being expert: the quest for cancer information on the Internet, Social Science & Medicine, 59, 1783-1793, 2004.
25) Lea M. Budden, Penny F Pierce, Barbara A. Hayes, Petra G. Buettner : Australian women's prediagnostic decision-making styles, relating to treatment choices for early breast cancer treatment, Res Theory Nurs Pract, 17(2), 117-136, 2003.
26) Wendy Levinson, Audiey Kao, Alma Kuby, Ronald A. Thisted : Not all patients want to participate in decision making; a national study of public preferences, JGIM, 20, 531-535, 2005.
27) Suzanne M. Miller: Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease: implications for cancer screening and management, Cancer, 76(2), 167-177, 1995.
28) Penny F. Pierce: Deciding on breast cancer treatment: a description of decision behavior, Nursing Research, 42(1), 22-28, 1993.
29) Barbara A. Vogel, Juergen Bengel, Almut W. Helmes: Information and decision making: patients needs and experiences in the course of breast cancer treatment, Patient Education and Counseling, 71, 79-85, 2008.
30) Augoustina Almyroudi, Lesley F. Denger, Vassiliki Paika, Nicholaos Pavidis, Thomas Hyphantis : Decision-making preferences and information needs among Greek breast cancer patients, Psycho-Oncology, www. interscience. wiley.com, 2010.
31) Katharine Kastbade Hughes: Decision making by patients with breast cancer: the role of information in treatment selection, Oncology Nursing Forum, 20(4), 623-628, 1993.
32) Nehama Lewis, Stacy W. Gray, Derek R. Freres, Robert C. Hornik: Examining cross-source engagement with cancer-related information and

its impact on doctor-patient relations, Health Communication, 24, 723-734, 2009.

33) Neeraj K. Arora Bradford W. Hesse, Barbara K. Rimer, K. Viswanath, Marla L. Clayman, Robert T. Croyle : Frustrated and confused: the American public rates its cancer-related information-seeking experiences, J Gen Intern Med, 23(3), 223-228, 2008.

34) Eilis McCaughan, Hugh McKenna: Never-ending making sense: towards a substantive theory of the information- seeking behavior of newly diagnosed cancer patients, Journal of Clinical Nursing, 16, 2096-2104, 2007.

35) Ellen Burke Beckjord, Lila J. Finney Rutten, Neeraj K. Arora, Richard P. Moser, and Bradford W. Hesse : Information processing and negative affect: evidence from the 2003 Health Information National Trends Survey, Health Psychology, 27(2), 249-257, 2008.

36) Charlotte E. Rees, Peter A. Bath: Information -seeking behaviors of women with breast cancer, REES, 28(5), 899-907, 2001.

37) Judith Belle Brown, June Carroll, Heather Boon, Jean Marmoreo: Women's decision-making about their health care: views over the life cycle, Patient Education and Counseling, 48, 225-231, 2002.

38) Keiichiro Adachi, Tokumi Ueno, Toshio Fujioka, Yutaka Fujitomi: Therapeutic decision-making and social support in Japanese breast cancer patients, Annual Report of Research and Clinical Center 9,1-7, 2010.

39) Elizabeth A. Grunfeld, E.Jane Maher et al: advanced breast cancer patients perception of decision making for palliative chemotherapy, Journal of clinical oncology, 24(7), 1090-1098, 2006.

乳がん女性の情報探索行動と意思決定の文献レビュー

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目的：この論文の目的は、乳がん女性の情報探索行動と意思決定の理論的そして実質的な関係を述べることである。

背景：乳がん患者はどのように治療方法を決めたらよいのか迷っていて、適切な情報にめぐり合うことが困難だと訴えている。

方法：文献は「情報探索行動と乳がんと意思決定」を検索語として1990年から2010年でPubMedと医中誌検索を用いて実施した。PubMedでは12件が適合したが、医中誌ではみられなかった。そのため、「情報探索と乳がん」、「意思決定と乳がん」で再検索を行った。

結果：この調査は情報探索行動の概念と、情報ニーズ、意思決定意向そして意思決定過程に分けて述べている。最初に概念と情報探索行動の重要性について述べた。次に情報ニーズと資料について述べた。そして、意思決定意向と経験の関係とそれらの評価について述べた。

結論：情報探索は最も良いと考えられる治療目標への到達と、病気からの回復、健康状態および人生の質の改善を目的としている。情報探索行動は治療の選択とがんへの対処行動である。乳がん患者が求める情報は個々人によって異なる。情報探索における経験は、患者の情報ニーズ、希望、意思決定意そして主観的満足度に基づき評価されている。

キーワード：情報探索行動、情報ニーズ、意思決定意向、情報探索経験

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